

# Standardising Clinical Caremaps: *Model, Method* and *Graphical Notation* for Caremap Specification

Scott McLachlan<sup>1</sup>[0000-0002-2528-8050], Evangelia Kyrimi<sup>1</sup>, Kudakwashe Dube<sup>2</sup>[0000-0002-2829-8481], and Norman Fenton<sup>1</sup>[0000-0003-2924-0510]

<sup>1</sup> Queen Mary, University of London, London, UK  
s.mclachlan(at)qmul.ac.uk

<sup>2</sup> Massey University, Palmerston North, NZ

**Abstract.** Standardising care can improve patient safety and outcomes, and reduce the cost of providing healthcare services. Caremaps were developed to standardise care, but contemporary caremaps are not standardised. Confusion persists in terms of terminology, structure, content and development process.. Unlike existing methods in the literature, the approach, model and notation presented in this chapter pays special attention to incorporation of clinical decision points as first-class citizens within the modelling process. The resulting caremap with decision points is evaluated through creation of a caremap for women with gestational diabetes mellitus. The proposed method was found to be an effective way for comprehensively specifying all features of caremaps in a standardised way that can be easily understood by clinicians. This chapter contributes a new standardised method, model and notation for caremap content, structure and development.

**Keywords:** Caremap, Clinical Documentation, Flow Diagrams

## 1 Introduction

Florence Nightingale introduced formal and descriptive documentation that would transform healthcare and become a vital component of effective care delivery [1]. *Clinical care process specification* (CCPS), or care modelling, which allows clinicians to create, amongst other things, caremaps that specify the workflow to be followed in caring for a patient suffering from a specific health condition [2] were developed from Nightingale's notation and reporting methods. While some CCPS present as templates to guide evidence-based care, others provide templates for charting individual patient needs, metrics or treatments. CCPS ensure continuity and quality of care for the patient [3, 1]. Most contemporary clinical documents were developed and refined during the 1980's and 1990's in response to a number of key needs, including: (i) the need to control costs; and, (ii) to improve the quality of patient care [4, 5]. Drawing on project management (PM) and total quality management (TQM) tools that were more common to industry, hospital managers attempted to reengineer hospital care processes with the aim of reducing clinical resource use and error rates, and improving patient outcomes [6, 7]. In spite of the potential for those reductions, clinical costs have continued to increase, and error rates continue to occur with distressing frequency [8].

Although the British Medical Association and Royal College of Nursing developed a joint guidance stating that use of standardised forms are beneficial in reducing variation in healthcare practice [9], a wide range of terms exist for CCPS, including:

- *Clinical practice guidelines* (CPG) [10] which are sometimes also known as:
  - *Consensus-based guidelines* (CBG) [11]; and,
  - *Local operating procedures* (LOP) [12, 13];
- *Clinical decision rules* (CDR) [14];
- *Clinical pathways* [15];
- *Care plans* [16];
- *Treatment protocols* [17]; and
- *Caremaps* [2, 18].

The key issue limiting the effectiveness of these terms is that authors do not agree on whether some of them represent distinct clinical documents [19-21], or are synonymous [22-24]. There is a clear lack of *standardisation of definitions, presentations and development processes for most types of clinical documentation*. While, for some of these terms, standardisation has been attempted, these attempts have either been incomplete or only further added to the confusion [25, 18, 26]. The use of different terms and versions of the same clinical care specification in different units within the same care facility, and between different care facilities, is becoming a serious problem. In the modern, increasingly digital, healthcare environment greater amounts of data are generated and captured daily, including from diagnostic devices used, or sensors worn by the patient while in the community. Any differences in the documentation approach or data recording method results in fragmented data, complicates the integration of data about the same patient from different sources, and inhibits health information exchange (HIE) [27, 28].

Researchers have proposed different approaches to develop CCPS and different ways of specifying them [25, 18]. These approaches vary greatly in their complexity level, design approach, content and representational structures [25, 18]. These variances lead to substantial and ubiquitous differences in communication and information transfer between clinicians providing care for the same patient. This affects the quality of care and introduces additional risk of harm for as many as 25% of all patients [29, 28]. Error reporting documentation is another area that also suffers from lack of standardisation. While clinicians and clinical researchers are professionally obliged and assumed to be honest and transparent in reporting identified errors, it is unlikely that current error statistics are representative of the entire scope of the problem [30-32].

Standardised CCPS ensures sufficiently high-quality information is recorded, enabling documents to be read quicker and content within to be better retained, all with the effect of improving overall patient safety and outcomes [29, 33, 34, 18, 35]. Standardised approaches to CCPS, ensure that each time a healthcare provider approaches each type of CCPS, the format and content are consistent with expectations [18].

Standardisation of CCPS brings many other benefits than purely operational or clinical. For example, a common problem with most clinical data is that they lack one or more of the elements of *integrity, integration and interoperability* (III). This has been

described as the *data triple-I issue* [36] and is presently seen as one of the biggest single barriers to Learning Health Systems (LHS) [36, 37]. Standardisation of CCPS make possible the support to mitigate the data triple-I issue, particularly *computer interpretability*, which in turn supports data standardisation and increases the chances for successful EHR and LHS implementation [37].

Unfortunately, there has been little research into the standardisation of caremaps and other results of clinical care process modelling [38, 39]. [25]. *The objective of this chapter is to address this challenge by exploring a model and graphical notation that makes it easy for clinicians to understand and allow clinicians to comprehensively specify caremaps.*

Supporters perceive care processes standardisation as an effective approach for dropping healthcare service variations and delivery cost, while at the same time maintaining or even increasing efficacy, quality and safety, improving patient experience and quality of life [40, 41]. However, healthcare is still one of the slowest sectors to accept and implement process standardisation, and to prove the positive impact on patient outcomes [42, 41]. This is due to clinician resistance as care standardisation is considered by many as ‘cookbook’ or ‘cookie cutter medicine’ that can only be effective after they have ruled out the unique needs of each individual [43-45, 41]. Given the overconsumption and financial crisis common to healthcare service delivery globally, standardisation of care processes can help clinicians provide managed care that is thought to decrease resource consumption and overall healthcare cost, and the incidence of inappropriate or ineffective care [46, 47].

### **Standardisation vs Innovation**

Standardisation is ubiquitous in our daily lives [48]. Examples might include the USA’s CAFÉ and similar international fuel economy standards used to govern efficiency and emissions of new motor vehicles offered for sale [49]; standards instituted for terminology and language, especially for mission-critical applications like satellite and aeronautical navigation systems [50] and air traffic control [51]; and standards used to ensure safe development, testing, production, prescription and administration of medicines [52, 53]. Standardisation has been described as the activity of establishing and recording a limited set of solutions to actual or potential matching problems directed at benefits for the party or parties involved in balancing their needs and intending and expecting that these solutions will be repeatedly or continuously used during a certain period by a substantial number of the parties for whom they are meant [54]. Standards generally consist of rules, guidelines, templates or characteristics for activities, or their results, that are provided for common and repeated use [55].

Innovation involves the development and implementation of a new or significantly improved product, service or process, and includes all scientific, technological, organisational, financial and commercial steps which are, or are intended to lead to the implementation of the innovation [56, 57]. Innovation in technology and strategy is both a catalyst for modern economic growth [58, 56], and standardisation [59, 60]. Yet standardisation, especially that which is unofficial or voluntary, is believed to be something that innately inhibits innovation [56, 61]. Growing insight into the role standardisation plays in enabling innovation is forcing reconsideration of this belief [56, 48, 62].

Several approaches have demonstrated the beneficial role standards can have in supporting innovation. Interoperability standards describe how different components in an ecosystem work together, for example, the hardware and software in ICT systems [63]. Anticipatory standards describe the operation and interoperation of components of future systems not yet in operation [64]. Formal standards are high-quality but have a considerable development lead time as they are carefully deliberated by standards-writing organisations, such as the International Standards Organisation (ISO) and International Engineering Task Force (IETF) [65]. De facto standards autonomously stem from processes and interactions within the ecosystem, such as the dominance of Microsoft's operating system in personal computing or resilience of the QWERTY keyboard layout which while being originally designed to mitigate adjacent keys jamming on early mechanical typewriters, is still seen on devices like touch screens which have no moving parts [65, 63]. Standards can also be described in terms of their particularisation or extent to which they are standardised: whether the organisation, service or approach is, for example, wholly, or largely, standardised [66].

Motor vehicle production and use is restrained by a great many standards: directing safety, materials application, pollution, operation and maintenance. The same standards governing fuel efficiency and emissions discussed earlier, and which have removed many vehicles with inefficient large-bore engines from sale, actually stimulated innovation. This innovation includes the recently released homogenous charge gasoline compression engines using a system described as Spark Controlled Compression Ignition (SCCI). SCCI is claimed to reduce fuel consumption by as much as 20% [67, 68]. The standards also produced competition in innovation with another major vehicle manufacturer also releasing new technology this year, the Variable Compression Turbocharged (VC-T) engine [69]. There were also innovations that delivered the fully electric vehicle (fEV) by Tesla: a product that sits in a market space that can only continue to innovate in order to meet anticipated standards requiring all passenger/com-muter vehicles to become electric [70, 71]. While the standards discussed operate to ensure that motor vehicles marketed today cause less pollution, they do not, for example, act inhibit a manufacturers choice of colour, luxury options or the model name that might adorn your next vehicle. And as we have seen, far from inhibiting innovation, standards can beneficially support novel innovations.

When it comes to the practice of medicine, a large array of standards applies to almost every action a clinician may seek to undertake. Built on a base of clinical practice guidelines, evidence-based medicine is perhaps the most broadly applied and well-known standardisation in medicine [26, 72]. This work investigates standardisation in the context of health informatics, finding current efforts often focus on some element of how the clinician interacts with the system, data entry, composition or presentation. In this review, no example was located that was investigating the potential for fundamental underlying issues to have arisen when non-standardised clinical documentation was digitised by a variety of hospitals and health sectors in the creation of EHR platforms. The clinical documentation that HIS and the now ubiquitous EHR were engaged to replace should be investigated as one potential source giving rise to the barriers that inhibited HIS and EHR adoption, and which currently restrain integration of LHS in clinical practice.

## 2 Literature Review and Related Works

### *Caremaps Background*

The term caremap refers to a graphical representation of the sequence of patient care activities to be performed for a specific medical condition suffered by either a patient or a cohort [73-75]. Caremaps have been in use, in one form or another, for around forty years [6, 76, 7]. Caremaps aim to standardise health care practice by organising and sequencing care workflow, ensuring standard of care, timely interventions and uniform outcomes using an appropriate level of resources [77, 25, 76, 73]. Caremaps also help track variance in clinical practice, as they provide a simple and effective visual method for identifying when care practice has deviated from the routine evidence-based pathway [78, 73].

The literature presents three different descriptions for the origin of caremaps, with distinct points of intersection between each that make it difficult to assess which may be the true history:

1. Caremaps were an output of the Centre for Case Management (CCM) in 1991 [79]. CCM's CareMaps were similar in form and function to existing clinical pathways and were applied to specific patient populations that were commonly treated in many hospitals [79]. CCM went on to trademark the double-capitalised version CareMap but had not within the first decade undertaken any research to demonstrate the effectiveness of the concept whose invention they claimed [80].
2. Caremaps naturally evolved as an expansion of earlier case management and care plans [7].
3. Caremaps were developed during the 1980's at the New England Medical Centre (NEMC) [81, 75].

Caremaps arose in nursing where they incorporate and extend the critical pathways and bring established project management methodologies into healthcare delivery [62, 57, 24]. Indeed, from the early 1980's nurses were the primary users of caremaps [68, 44].

### *Caremap Terminology*

Definitions from literature of the early- to mid 1990's in principle agreed that the caremap presents as a graph or schedule of care activities described *on a timeline* and *performed as part of the patient's treatment by a multidisciplinary team* to produce *identified health outcomes* [77, 2, 76, 73-75, 7]. Even though the structure and content of caremaps has changed markedly during the last three decades, this general definition still applies.

Caremaps can be observed under three similar but different titles: (i) caremaps; (ii) CareMaps; and (iii) care maps. The first, *caremaps*, appears to have been the original title prior to the CCM trademarking the second, *CareMaps*, in the early 1990's [77, 79]. In literature published after 1994 that uses the first, *caremaps*, it is not uncommon to also see some mention of CCM or their trademark [82] although this is not always the case [83, 84]. The use of *care maps* has also been seen, possibly as a defence to potential

issues that might arise from confusion with the CCM trademark, as no author used this third type in context or with reference to the CCM [73, 85].

There is disagreement on whether caremaps are a separate format of clinical tool [19-21], or simply another term for care pathways, clinical pathways, critical pathways and care plans [22-24]. This disagreement is exemplified by flow diagrams that are internally describe as a “care map”, yet are captioned ‘clinical pathway’ by the author (e.g. in Figure 1 of Thompson et al [86] and Figure 5 on page 45 of Yazbeck [87]). Yazbeck (ibid) further presents a number of similar flow diagrams for care management, describing them using a range of terms including ‘care map’, ‘care pathway’, and ‘algorithm’.

### Caremap Evolution and Current Context

Starting in the early 1990’s, Nursing caremaps were more textual than their contemporary counterparts, and had a structure made up of two components: (1) *Problem and Outcomes Specification*: identifying patient problems and necessary outcomes within a time-frame; and (2) *Task and Activity Specification*: a breakdown and description of day-by-day tasks and activities on a critical path [73, 74]. Later approaches specified the care map in three components: (1) *the flow chart diagram*; (2) the transitional text-based *care map of activities* broken down day-to-day, and; (3) the *evidence* base relied upon in their construction [78]. These methods of specifying and presenting the caremap may have resulted in the terminology confusion that still persists today. More recent caremaps are specified as a flow diagram made up of clinical options for a particular condition. Thus, modern caremaps contain multiple possible paths based on: (i) symptomatology; (ii) diagnostic results, and; (iii) how the patient responds to treatment [88, 89].

*Traditional caremaps* considered elements such as anxiety, rehabilitation, education, prevention and coping strategies and were intended to restore the patient as close to a normal quality of life as was possible given their diagnosis [73-75]. Starting from 1999 there began to be examples of *transitional caremaps*: while still being text-based, these were limited to interventions necessary to treat the primary diagnosis [25, 82]. As caremaps evolved into graphical representations we observe *contemporary caremaps* presented as separate but complementary components to the clinical pathway or CPG [79, 84]. A summary of the relevant elements of each caremap type is presented in Table 1.

**Table 1.** Summary and comparison of caremap evolution stages (from [18])

|                       | <b>Traditional</b><br>(1980’s to mid-1990’s) * | <b>Transitional</b><br>(Mid-1990’s to mid 2000’s) * | <b>Contemporary</b><br>(2004 onwards) *                 |
|-----------------------|--|---|---|
| <b>Primary Author</b> | Nurses   | Nurses and Doctors                                  | Doctors   |
| <b>Context</b>        | Holistic                                       | Primary condition                                   | Single diagnostic, screening and/or intervention event. |

|                     |                                      |  |   |
|---------------------|--------------------------------------|--|---|
| <b>Foci</b>         | Restoring the patient to normal life | Outcomes, cost and resource consumption                | Efficiency of care delivery and outcomes, reduction of practice variation, bridge the gap between evidence and practice |
| <b>Presentation</b> | Text-based                           | Text-based with some early flow examples               | Flow diagram or graph   |
| <b>Status</b>       | Independent document                 | Independent or sometimes incorporated with CP document | Self-contained but often found appended to/contained in CPG   |

Caremaps are found in many healthcare domains, including: *paediatric surgery* [88], *nursing* [89], *oncology* [90], *diagnostic imaging* [91], *obstetrics* [4] and *cardiology* [76]. Even within these examples, there exists significant variance in complexity level, design approach, content and the representational structures used.

### Related Works: Efforts to Standardise Caremaps

Numerous contemporary caremap examples were found annexed to hospital-based clinical CPGs. Contemporary caremap literature tended to focus on establishing the clinical condition justifying creation of the caremap, such as: determination of incidence, risk factors and patient outcomes [88]; diagnosis and stabilisation of patients with an acute presentation [89]; and, protocolising of ongoing treatment [85]. Presentation or discussion of a development process or the elements used in construction were rare, and more often had to be inferred from a thorough reading of each paper.

We found a single article written by a veterinarian and a lawyer which attempted a systematic description of the process for contemporary caremap development [92]. This article primarily focused on standardisation for the purpose of cost containment, and provides an example of mapping for a surgical procedure [92]. Given their focus and particular caremap construction model which, through their own exemplar application, only includes a temporally-ordered single-path representation of the gross steps of patient care, their paper was at best, merely formative. By their own admission, they deliberately limited relevant data analysed during the input design phase to what they felt was truly critical for identifying and understanding outliers. This results in a model lacking clinical applicability and a distinct lack of detail surrounding each care process. Their method requires significant work to adequately support true standardised clinical caremap development.

Hospital management and clinical literature opinions changed during the early 2000's, with a distinct focus shift towards the theme of standardisation [93, 6, 94, 7]. Researchers, politicians, those engaged in hospital governance, and some clinicians recognised standardisation should be considered of paramount importance to the future of healthcare delivery [94]. Standardisation of such things as clinical decisions, diagnostic and therapeutic methods, evidence-based guidelines, care approaches, practice standards and clinical information was sought [95, 8, 94, 5]. Standardisation in the name of quality care and outcomes would become the single-minded national focus of

healthcare service delivery for entire countries [95, 5]. Promoted with great passion, this type of standardisation has seen multiple teams within the same country, or even within the same organisation, expending effort on developing standardisation frameworks with some degree of similarity and overlap [96-98]. However, this drive towards standardisation has had little effect on the definition, development and structure of much of the current clinical documentation, because as we approached the end of the first full decade of standardisation, calls for standardised clinical care documents continue to increase [95, 99, 38, 18, 39, 100]. An unmet need can also be seen in calls to resolve poorly standardised taxonomy and nomenclatures currently used in developing and cataloguing clinical documentation [101].

### 3 Research Process and Methodology

**Literature Review:** A search was conducted across a range of databases using the terms ‘caremap’, ‘CareMap’, and ‘care map’. A citation search drawn from all included papers was also performed. This search identified 1,747 papers. Once duplicates, papers not based in the nursing, medical or healthcare domains, and those using the term “care map” in other contexts were removed a core pool of 115 papers remained.

**Development of Review Framework Using Thematic Analysis:** Initially, each paper was reviewed using content and thematic analysis [102] and concept analysis [103] to identify and classify terminology, construction and content elements and to infer the caremap development processes.

**Methodology for Standardisation of Caremaps:** Literature reviews have a ground-level consensus forming function that allows for identification of implementation techniques and the degree of accord between authors within a domain [104, 105]. The literature pool was used to identify common definition, structure and content elements for caremaps. In addition, process steps that were consistently described led us to a standardised caremap development process.

**Methodology for Evaluation of Proposed Standard for Caremaps:** Case Studies are a grounded comparative research methodology with a well-developed history, robust qualitative procedures and process validation [106]. The case study approach provides a real-life perspective on observed interactions and is regularly used in information sciences [107, 108]. Case studies are considered as developed and validated as any other scientific method and are an accepted method where more rigid approaches to experimental research cannot or do not apply [109, 110]. The standardised development process and resulting caremap are both evaluated using case studies of examples from the authors’ other works.



## 4 Standardisation of Caremaps: *Exemplar for Standardising CCPS*

### Clinical Decisions in Caremaps

Graphically modelling patient care for a given medical condition is not new. Several approaches and presentation styles have been proposed, including: *UML process modelling* to represent the ongoing clinical management of a chronic condition [111]; *business process modelling notation* (BPMN) to visually map the treatment flow captured in clinical pathways [112]; and, *influence diagrams* to model the structure of complex clinical problems, identifying **decisions** to be made, *the sequence in which those decisions may arise*, *the information available to make the decision* and *the probability of uncertain events* [113]. Caremaps presentation style and content has changed significantly since their conception in the 1980's. Currently, contemporary caremaps used in clinical medicine present as an immature information visualisation approach [18]. Apart from lacking standardisation, existing caremaps lack also a comprehensive representation of clinical **decision points** (DP).

Until recently, caremaps lacked standardisation in structure, content and development [18]. The authors proposed and presented what is stated here as TaSC (*Towards a Standard for Caremaps*): a model for standardising the development and presentation of clinical caremaps [18]. Based on TaSC, each node within the caremap represents activities related to patient care. In addition, nodes are often seen to represent one or more latent clinical decisions, such as selecting the appropriate treatment path for each patient. Our prior work has pointed out the presence of these latent DPs within caremaps as well as the absence of a way to identify and represent them [18]. This chapter explores these issues and proposes an extension to TaSC for identifying and representing DPs with decision criterion.

There are several clinical decisions that might be embedded within a caremap node. For instance, a treatment activity may require the clinician to consider whether aseptic technique is required, which dressing to use or which clinical resource to assist during treatment. The majority of these decisions have no direct impact on the flow of care or the pathway of the patient within the caremap. Thus, only decisions that have an impact on the path to be taken by the patient should be considered as separate DPs within the caremap.

Clinical decisions that may lead to DPs in a caremap result from six aspects of clinical activities identified by Richardson et al [114] as follows:

**Clinical Evidence:** The identification and selection of clinical evidence from clinical trials and clinical practice guidelines for use in creating tools like caremaps necessitates decisions regarding how to gather the right clinical findings properly and interpret them soundly.

**Diagnosis:** During diagnosis decisions are made regarding the selection and interpretation of diagnostic tests.

**Prognosis:** Prognosis requires decisions of how to anticipate a given patient's likely course.

**Therapy:** Therapy decisions consider how to select treatments that do more good than harm.

**Prevention:** Screening and reducing a patient's risk for disease prevention decisions.

**Education:** Consideration of how to teach the clinician, patient or patient's family what is needed fall within the remit of education decisions.

## 5 Approach and Method for Standardising the Model and Notation for Caremap Specifications

This section describes the current state, and potential starting point for any standard for caremaps, as resolved from the review of the literature.

### Caremap Development Process with *Consensus Formation*

The literature was used initially to establish consensus on common structure, content and development processes that had previously been used in the creation of caremaps, and which may be relevant in defining standard caremap and development processes. The case studies were used to evaluate and refine the elements of each.

To address the stated aim of this research, we focused our research on tertiary care (hospital-borne) caremaps and specifically the following three components whose characteristics came out of the thematic analysis, and make up the review framework.

|                    |   |
|--------------------|---|
| <i>Structure</i>   | What is the representational structure and notation for expressing contemporary caremaps? |
| <i>Content</i>     | What content types are consistently seen in contemporary caremaps?                        |
| <i>Development</i> | What are the process steps followed for developing contemporary caremaps?                 |

### Standardising the Caremap Structure

Each caremap flow diagram identified from the literature had its own visual element and notation style. The most common observed was a rectangle for representing the process step, which are usually called an activity. Contemporary caremaps contain a set of nodes that represent patient care activities. However, the literature shows there is no consistency in the way an activity may be represented. Different shapes including rectangular boxes with rounded [86] or squared corners [93, 115, 85], plain text [79], or even arrows [116] have been used. In some cases, activities that diverge to different

and mutually exclusive pathways may be represented by a diamond [23, 115]. The flow from one activity to another has been illustrated with arrows [88, 78, 115], or simple lines [79, 23]. The literature also lacks clarity as to whether a caremap should have entry and exit points. In some cases, neither is present [78, 86], while in others these points are an implicit [23] or explicit part of the diagram [115]. Finally, most caremaps contained multiple pathways and were sometimes presented as multi-level flow charts [93, 115].

### **Standardising the Caremap Content**

An activity in the caremap represents a specific medical process. Three broad medical activities that are regularly observed are; diagnosis, treatment and ongoing monitoring/management [117, 86]. A set of desired outcomes is a common caremap component [88, 93, 115, 85]. Time, presented either as a duration or a dynamic care process, is often included in the caremap [84]. Finally, an explanation related to the activities and/or the arrows might also be part of the caremap [88, 78, 84, 86]. The former helps to better describe an activity, while the latter to justify the flow transition from one activity to another and/or the path to be taken based on the clinical decision being made.

### **Standardising the Caremap Development Process**

The process of developing a contemporary caremap is a research topic that has been frequently neglected. Only one in every six papers gives any information concerning the development process. Unfortunately, very few papers provide any clear description of the development process [44, 117, 86]. For the remaining, the caremap development process can only be inferred [79, 115, 85].

## **6 TaSC: Proposed Standard for Caremaps**

This section presents a solution for standardising caremap structure and content, and an approach for caremap development distilled directly from analysis of the CCPS literature. During the course of refining and evaluating TaSC the presence of previously undescribed DPs that would be assistive in identifying the appropriate treatment path for patients was realised. As a result, TaSC also incorporates a standard approach to describing DPs relevant to path selection, and based around the six aspects of clinical work from which clinical decisions arise listed earlier.

### **Standardising Caremap Structure**

The TaSC entity relationship model shown in Figure 2 describes the relationships among the caremap's structural elements. All elements and their notation are presented in Table 2. The standardised structural model for the caremap is then demonstrated in the content model shown in Figure 3.

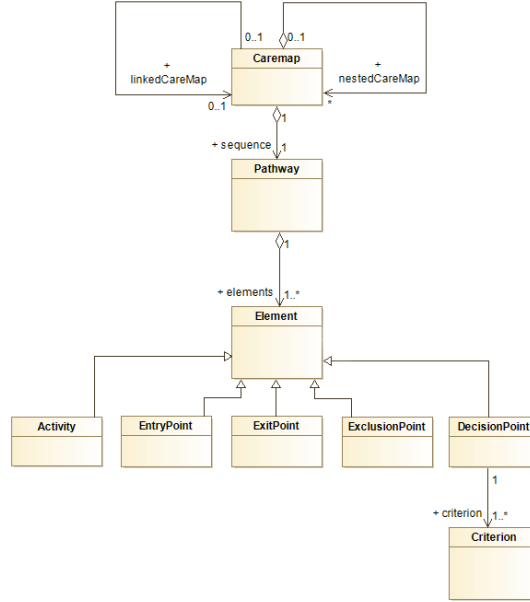









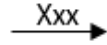

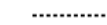


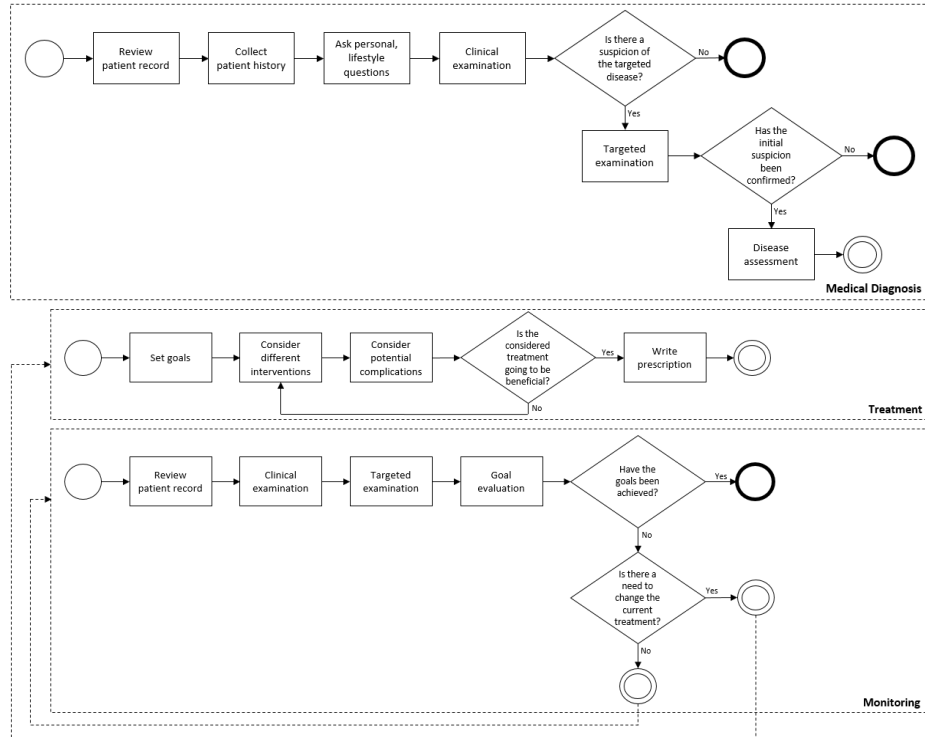
Figure 2: An Entity Relationship model for the caremap

Figure 2 presents the model for the caremap specification that we believe has the key features necessary to comprehensively specify a clinical caremap by using a minimal set of representational constructs or elements. The representational elements of the caremap in this model lead to a representation notation that is simple and easy for clinicians to understand and use in authoring caremaps. In the caremap model, which is presented by using the UML class diagram, the caremap can either nest or link to another caremap. A caremap contains Pathways such that each present as a sequence of Elements. These include the Activity nodes within which clinical efforts occur, as well as the functional EntryPoint, ExitPoint, ExclusionPoint and DecisionPoint (DP) elements. Each DP represents some clinical decision to be made based on one or more Criterion, which can include such things as the patient's risk factors, symptomatology and response to treatment, and often as identified from the results of clinical tests. The Pathway describes both: (i) the timing of necessary activities, that is, when activities should occur and how long to wait before performing the next activity; and, (ii) the route or selected order of events identified as a result of the impact of DP Criterion.

Corresponding to each representational construct presented in the caremap model in Figure 2, a set of notational elements have been designed to allow caremaps to be specified according to the model. Table 2 presents the notation to represent each caremap element in the model. The notation is inspired by the standardised pictorial approach of UML. The application and use for each element is described within Table 2.

**Table 2:** The TaSC Content type, activities and decisions (adapted from [18])

|    | Element                               | Description   | Notation  |
|----|---------------------------------------|---|---|
| 1  | <i>Entry point</i>                    | Beginning of the caremap  |    |
| 2  | <i>Exit point</i>                     | End of the caremap  |    |
| 3  | <i>Exclusion point</i>                | Exclusion from the caremap, as the patient does not belong to the targeted population   |    |
| 4  | <i>Activity</i>                       | A care or medical intervention that is associated with a medical content type ( <i>see Table X in next section</i> )                      |    |
| 5  | <i>Nested Activity</i>                | An activity that has an underlying caremap  |    |
| 6  | <i>Decision</i>                       | A cognitive process of selecting a course of action that is associated with a medical content type ( <i>see Table X in next section</i> ) |    |
| 7  | <i>Nested Decision</i>                | A decision that has an underlying caremap   |  |
| 8  | <i>Flow</i>                           | Transition from one activity to another along the pathway   |  |
| 9  | <i>Multiple pathways</i>              | Flow from an antecedent activity to a number of successors from which a decision point arises   |  |
| 10 | <i>Decision Criterion</i>             | Conditional values used to identify the path to be taken based on the clinical decision being made  |  |
| 11 | <i>Nested caremap connection</i>      | Connection between an activity and its nested caremap   |  |
| 12 | <i>Multi-level caremap connection</i> | Connection between a series of linked caremaps  |  |



**Figure 3:** The TaSC content model for the caremap (adapted from [18])

### Standardising Caremap Content

Diagnosis, treatment and ongoing management/ monitoring are the three main content types captured in TaSC. As shown in Table 3, these three broad content types are related to a set of specific medical activities, the information captured, and relevant DPs. Finally, referring back to the content model presented previously in Figure 3 we see that each content type represents a different caremap level, and that the activities and decisions are components of the caremap

**Table 3:** Caremap content type, activities, data and decisions (adapted from [18])

| Content Type | Activity (associated with Content Type) | Data/ Information Captured      | Decision (associated with Content Type)       |
|--------------|---|---------------------------------|---|
|              | Review patient records                  | Demographics<br>Medical history | Is there a suspicion of the targeted disease? |
|              | Collect patient history                 | Family history<br>Comorbidities |   |

|            |                                   |  |   |
|------------|-----------------------------------|--|---|
| Diagnosis  | Ask personal, lifestyle questions | Habits (risk factors)                      | Has the initial suspicion been confirmed?   |
|            | Clinical examination              | Signs/ Symptoms                            |   |
|            | Targeted examination              | Diagnostic test results                    |   |
|            | Disease assessment                | Diagnosis                                  |   |
| Treatment  | Set goals                         | Expected outcomes                          | Is the considered treatment going to be beneficial?                                   |
|            | Consider different interventions  | Possible treatments                        |   |
|            | Consider potential complications  | Variances from expected outcomes           |   |
|            | Write prescription                | Selected treatment<br>Treatment details    |   |
| Monitoring | Review patient records            | Previous test results<br>Previous symptoms | Have the goals been achieved?<br><br>Is there a need to change the current treatment? |
|            | Clinical examination              | Signs/ Symptoms                            |   |
|            | Targeted examination              | Diagnostic test results                    |   |
|            | Evaluate goals                    | Progression                                |   |

### Standardising the Caremap Development Process

TaSC development process is divided into 6 phases, as shown in Figure 4. The development steps have been clustered into three primary groups: (a) those undertaken before caremap development commenced; (b) those undertaken during development and refinement of the caremap, and; (c) those that come after the caremap has been refined and approved for implementation. At first, the conceptual framework should be decided and a multidisciplinary team should be assembled. In the next phase it is important to clarify and challenge current practice. The knowledge and current data should be studied and potential variations from the current practice should be anticipated. Reviewing and evaluating the available evidence is the last phase before caremap development. Figure 4 illustrates that as new knowledge becomes available and more lessons are learned through caremap evaluation and implementation, the caremap should be revised [117].

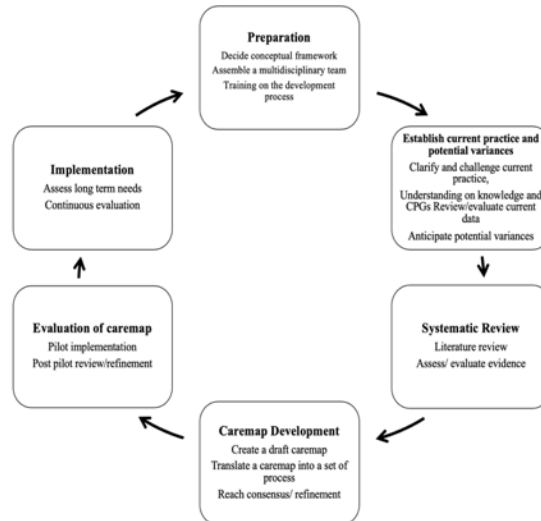


Figure 4: Caremap development lifecycle [18]

## 7 Evaluation: A Study Using TaSC to Develop and Specify Caremaps in a Standardised Way

As part of a project to design and build LHS intended to reducing clinical overuse while empowering patients to actively participate in their own healthcare, the EPSRC-funded PAMBAYESIAN project ([www.pambayesian.org](http://www.pambayesian.org)) is creating Bayesian Network (BN) models to predict treatment needs for individual mothers with gestational diabetes mellitus (GDM). The process initially required us to create three caremaps for: (1) diagnosis; (2) management, and; (3) postnatal follow up.

**Inputs:** Inputs were: (a) clinical practice guidelines for the care of women with diabetes in pregnancy; and, (b) review and consensus from midwives and diabetologists.

**Development:** An iterative development process was used wherein the decision scientist and midwifery fellow worked together to deliver an initial version of the caremap based on the CPG and clinical experience. This initial caremap was revised and refined during a number of sessions with clinicians. Figure 5a presents the resulting clinical management caremap for GDM.

**Extending the Caremaps:** While using the caremaps to develop BNs for supporting diagnostic and treatment decisions for GDM we found the process was significantly simpler and more efficient when latent decisions relevant to selecting the appropriate treatment path for patients, and embedded in each caremap, were identified and included in the caremap. The GDM caremaps were redeveloped as caremaps with DPs. Figure 5b shows the same clinical management caremap, however the DP have now been expounded in place of the previous activity node.

**Validation:** Validation was performed through consultation seeking consensus from three diabetologists with tertiary care experience of obstetric patients managed using the CPGs used in the caremaps' creation.



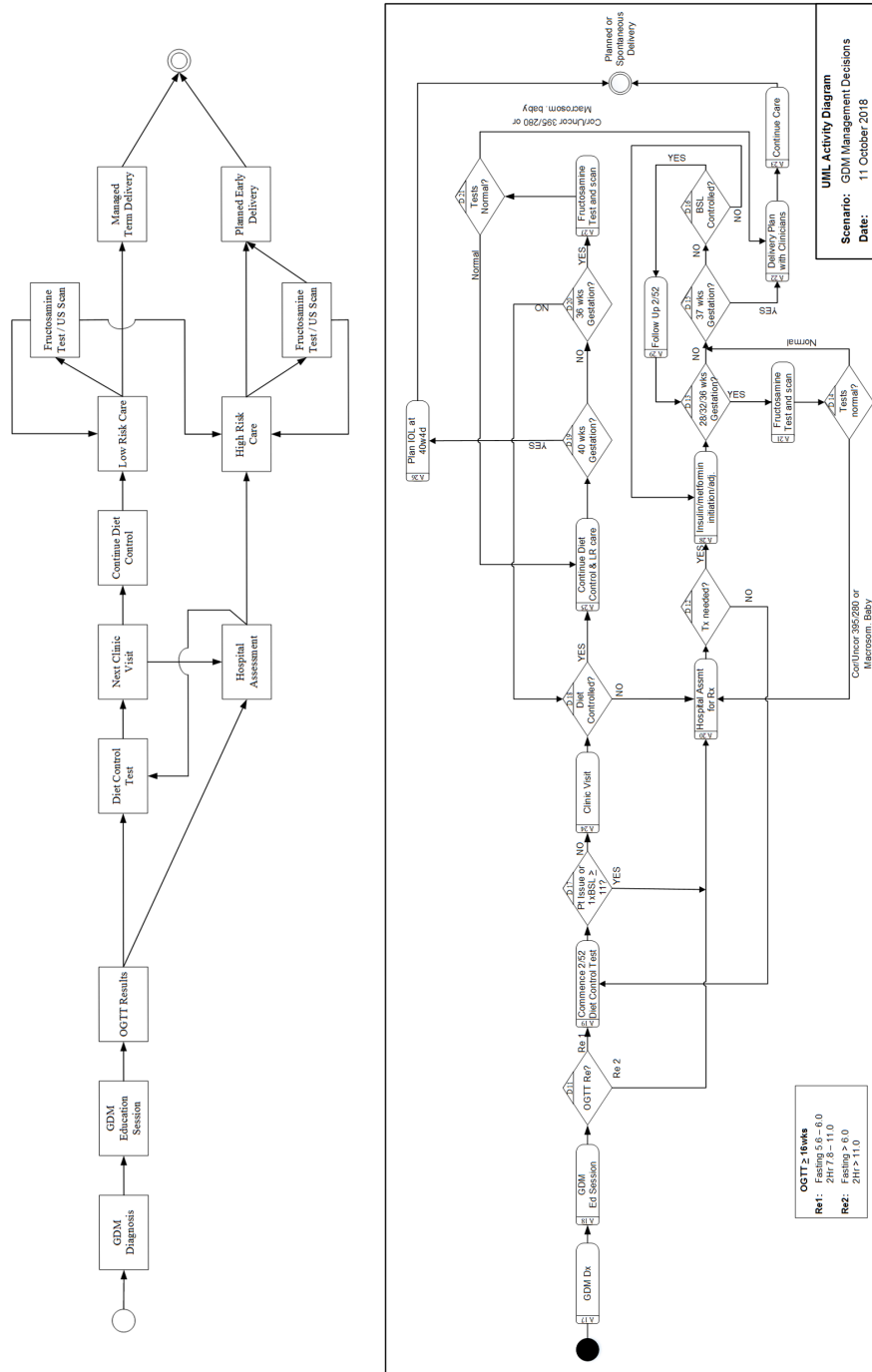


Figure 5: (a) GDM Management without DP [18]

### (b) GDM Management with DP

## 8 Summary and Conclusions

Standardisation of care through the means of guidelines and caremaps is sometimes seen as limiting clinicians' ability to make decisions based on the patient presenting before them, seemingly giving rise to *cookie-cutter medicine*. A range of clinical care process specification (CCPS) documents exist. The disagreement that persists within the domain regarding their name, form and function shows that they are not standardised. This lack of standardisation can put patients at risk, and has in some cases, caused harm. One type of CCPS, *caremaps*, are a form of standardised clinical documentation that can improve patient safety and outcomes while prompting clinicians with information and visual cues necessary to clinical decisions regarding the appropriate treatment path for their patients. Caremaps have evolved during the last three decades from primarily text-based presentations developed by nurses, to flow-based visual aids prepared by doctors to be representative of diagnostic and treatment processes. These contemporary caremaps have been presented in a variety of ways and with vastly different levels of content. Contemporary caremaps lacked standardisation.

This chapter presented one solution for standardising caremap structure, content and clinical decisions, and an approach for caremap development distilled directly from analysis of the collected pool of academic literature. The development process was evaluated and refined during the development of caremaps for management of patients with GDM. The resulting caremaps were validated by expert consensus.

If used consistently, the methods presented in this chapter could bring standardisation to caremaps and ensure that as clinical staff move between busy units in a tertiary care setting, they are not distracted from the patient in an effort to understand the care flow model. Every caremap would be familiar and time can be given over to treating their patient, not trying to understand the document.

Future work should address a standard approach for digital development and imputation of the caremap by clinicians, and representation of caremap logic in other computer-aware and algorithmic forms including BNs and Influence Diagrams (Fenton and Neil 2018). These can form part of an LHS and aid in the making of population-to-patient level predictions about treatment and health outcomes.

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